

Programs for the Handicapped

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HIGHLIGHTS

**The Federal Dollar
In the Disability Field**

**High-tech and Low-tech
In Rehabilitation**

**Restructuring Medicaid:
An Agenda for Change**

**New Role for the National Council
On the Handicapped**

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The Federal Dollar in the Disability Field

By Helga Roth

How much the Federal government spends for disabled people, is a popular question. The inquirer who expects a definitive, global figure as a response will be disappointed. What he gets is a lengthy answer full of complexities and every figure quoted accompanied by a host of caveats on what it does and does not include

There are many reasons for this information problem. An important one is that handicapped individuals are also of various ages, they can be poor or part of a minority group, they may be veterans or wear some other hat which makes them eligible for programs targeted towards any of these populations. How could money spent on entitlements or on services to these groups be counted in the total figure for expenditures on disabled persons? Nobody has found a precise way without increasing the reporting burdens of state governments and program managers.

Federal funds for the disabled fall into distinct categories:

- support for programs whose primary mission is to assist handicapped individuals, i.e., Handicapped Preschool and School Programs;
- income maintenance specifically for disabled individuals, e.g., Social Security Disability Insurance;
- support for programs which are legislatively mandated to spend a certain percentage of program funds for handicapped participants, e.g., the Head Start Program (10%);
- income maintenance for groups which explicitly include the disabled population: Supplemental Security Income (for the aged and persons with disabilities);
- support of programs which include services for handicapped persons but do not single them out within the population served, e.g., Child Welfare Services;
- medical insurance programs benefiting the handicapped among the eligible population, e.g., Medicaid.

This rough categorization indicates another important distinction: categorical programs versus entitlement programs. Money for categorical programs is authorized and appropriated by Congress according to laws which express the will of the Congress to achieve certain goals in education, health, housing, and social services. Recipients of these funds are states or local governments or public or private institutions and organizations. Funds disbursed for entitlement programs go to individuals who meet certain eligibility criteria. They can be for unrestricted use such as pensions for disabled workers or supplemental security income or cover certain allowable expenses such as hospital stays, medical tests, etc.

It is also useful to distinguish among the ways money is dispensed for categorical programs:

Formula Grants: Federal money is received by the states and administered according to broad Federal guidelines. The amount a state agency receives is determined by a complex formula that takes into account the size of the population to be served, the poverty level in the state and other considerations. Examples in the handicapped field are "Handicapped Preschool and School Programs" which assist states in defraying the costs of educating disabled children in their public school systems, or the "Rehabilitation Services and Facilities—Basic Support Program" which helps states cover the costs of vocational rehabilitation services. States are required to file state plans showing that money will be used according to the federal regulations for the specific program

Discretionary Grants Funds for discretionary grants are directly administered by Federal offices. Eligible applicants for these funds include government entities, non-profit organizations, institutions of higher learning and others. As a rule discretionary grants are used to support research, e.g., Handicapped Research and Demonstration; development of manpower, e.g., Rehabilitation Training and Demonstration; and demonstration programs, e.g., Handicapped Early Childhood Assistance.

Block Grants: The states receive funds under broad guidelines and much of the decision-making on using the money is left to the state agencies. An example is the Maternal and Child Health Block Grant which provides for health services to mothers and children. Crippled children services were merged into the block grant as were Comprehensive Hemophilia Diagnostic and Treatment Centers and Genetic Disease Testing and Counseling. States can now decide whether to provide these services and how much they will spend on them.

After establishing the typology of Federal funding patterns, a closer look at the disability field is in order. The first group of programs described below are **service programs** which for purposes of this article include: education, employment, health, housing, social services and transportation.

Education

Programs which focus specifically on the education of handicapped children, youth and adults add up to \$1,305,535,000 for Fiscal Year 1984 and include the basic Federal aid to states which is a formula grant to assist with expenses to educate their disabled student population and eight smaller discretionary grants for personnel preparation, early childhood education, and deaf-blind centers, to name a few. This education outlay is supplemented by the ten percent that vocational education programs and the Head Start programs are mandated to spend for handicapped individuals, and also by funds for special services to disadvantaged students. Many young

handicapped people qualify for these special services because of their low-income status

Employment/Vocational Training

Employment/vocational training of handicapped people was allocated \$1,254,784,000 for Fiscal Year 1984. The largest percentage was designated to the formula grant that helps support vocational rehabilitation services in the states. The Veterans Administration spends another \$130,852,000 to provide vocational rehabilitation for disabled veterans. Discretionary grants are available for manpower training in rehabilitation and for special programs for handicapped American Indians, disabled migrant workers, programs with industry and others. An unknown share of some \$700,000,000 that supports the employment services of the Labor Department in all states is spent on assistance for handicapped job seekers, who by law are entitled to special help in the employment security offices across the nation.

Health

Most health services are block granted and therefore expenditures for disabled people cannot be readily aggregated on the Federal level. Funds from the Maternal and Child Health (MCH) Block Grant can be used for Crippled Children Services which has a long history and tradition. Comprehensive Hemophilia Diagnostic and Treatment Centers and Genetic Disease and Counseling Programs are also covered by the MCH Block Grant.

Services for mentally handicapped individuals are provided under the Alcohol and Drug Abuse and Mental Health Services Block Grant. The Preventive Health and Health Services Block Grant includes money for home health services, hypertension programs and health education, among other programs. The Primary Care Block Grant assists states in delivering services through community health centers.

The Veterans Administration spends a sizeable sum on hospitalization and outpatient care, domiciliary nursing home care which benefit both disabled and chronically ill veterans. In addition \$86,862,000 are earmarked for veterans' prosthetic appliances.

By far the largest number of health dollars are disbursed through Medicare and Medicaid, discussed below under "Entitlement Programs."

Housing

In the housing field the picture is very different. The Veterans Administration administers two programs which exclusively serve handicapped individuals: one provides direct payments to eligible veterans for adapting housing and the other is a loan program for eligible disabled veterans to buy a home.

The Department of Housing and Urban Development administers a program called "Housing for the Elderly and Handicapped" which provides loans to private nonprofit organizations or consumer cooperatives to finance construction or rehabilitation of rented dwellings for the elderly

and disabled population. Another very small program makes money available for congregate housing services which include meal services and other nonmedical services necessary to prevent institutionalization. These four programs add up to \$494,750,000 for Fiscal Year 1984, but this amount is not the total spent for housing for the disabled. Both the Farmer's Home Administration and the Department of Housing and Urban Development have a variety of programs to assist low income people, and since many handicapped persons are in this category they may be eligible for loans, mortgage insurance, interest reduction and other programs. The handicapped community in a city which applies for Community Development Block Grant funds can also benefit because construction, rehabilitation of and site acquisition for centers for the handicapped are allowable expenses. This will not happen, however, unless the handicapped community participates in the design of the program and such a handicapped center becomes part of the whole package.

Social Services

The services discussed under this category provide a mix of services and therefore could also be considered health or employment related. The Developmental Disabilities programs, Independent Living Centers and Books for the Blind and Physically Handicapped are included. Funds amount to \$117,101,000.

The largest portion of funding for social services comes from Title XX, the Social Services Block Grant program. States can decide, within guidelines, how much they want to spend on services for their handicapped populations. Some report to the Federal administering office on how much they spend, others do not, making it impossible to aggregate expenditures on the Federal level. There are a number of other social services which include handicapped beneficiaries such as child welfare services, child adoption assistance, or weatherization assistance.

Transportation

There is one program in the transportation area that serves disabled people exclusively. It is administered by the Veterans Administration and provides money for disabled veterans to adapt their vehicles. In 1984 the VA will spend an estimated \$14,284,000 for this program.

In the Urban Mass Transportation Administration (UMTA), U.S. Department of Transportation, under the Capital Improvement Grants Program, about \$25,000,000 are earmarked annually to go to private nonprofit organizations for the purpose of providing transportation to the elderly and handicapped. These funds can only be used for the purchase of special vehicles, not for operation of a transportation program.

It is impossible to provide a global figure of what mass transportation systems built with Federal money have spent on making these systems accessible or providing alternative services for handicapped people. However, the Department of Transportation has published a notice of proposed rulemaking in the September 8, 1983 *Federal Register* which includes a cost cap of what local pub-

lic transportation systems would be required to spend: 7.1 percent of the recipient's UMTA assistance or 3 percent of the total operating budget. The final word on which of the two fiscal arrangements will prevail is not in, but some services for handicapped individuals will be required of all UMTA recipients.

Social Services, FY 1983

Education	\$1,262,010,000
Employment/Vocational Training	1,190,124,000
Health	84,735,000
Housing (includes elderly nondisabled)	655,425,000
Social Services	112,999,000
Transportation	38,630,000
	<hr/>
	\$3,343,923,000

Note: The figures used in the above table are for Fiscal Year 1983, making it comparable to the table for income maintenance for which only 1983 figures were available. However, in the text, figures for Fiscal Year 1984 were used.

Research

The research field is one of the most difficult areas in which to decide what to include or exclude to arrive at a total expenditure figure. Research relevant to the disability field goes on in about 32 Federal agencies. Four of these have sizeable programs: the National Institute of Handicapped Research (NIHR), (all research is in the disability field); Special Education Programs (SEP), (research on improvement of education of handicapped children and youth); the National Institutes of Health (research to find the cause and cure of diseases and disabling conditions); and the Veterans Administration (medical research conducted intramurally in VA medical centers and clinics). In other agencies such as the Labor Department, the Transportation Department, the Social Security Administration, the National Science Foundation, etc., smaller research programs are funded which are appropriate to the agency's mission with an aspect relevant to the disability field.

Research programs cannot be separated into neat categories. Basic research on nerve cells may lead to tomorrow's breakthrough for treatment of paraplegia. To understand the cause of a disabling condition may be the important step towards prevention. Scientists may focus on cures, on amelioration, or on maintenance of a patient. Any total expenditure figure for these activities would be arbitrary at best.

The National Institute of Handicapped Research (NIHR) made an effort to gather figures on research revolving around rehabilitation of disabled persons. According to reports of 27 Federal agencies, they spent a total of \$198,369,000 on rehabilitation related research in 1983. This figure includes \$28,000,000 expended by NIHR, \$2,000,000 by the Rehabilitation Services Administration, and \$12,000,000 by Special Education Programs.

Special Institutions

We would be remiss if we did not mention Federal funding for special institutions in the disability field. The American Printing House for the Blind receives \$5,000,000; \$26,300,000 are earmarked for the National Technical Institute for the Deaf, which provides two to three year technical education to deaf and severely hearing impaired students; and \$52,000,000 support Gallaudet College, a unique institution which provides higher education for deaf students and operates a Model Secondary School for the Deaf and the Kendall Demonstration Elementary School for the Deaf. The Helen Keller Center for the Deaf-Blind is supported with \$3,700,000.

Income Maintenance and Insurance

The megabucks—a reported \$70 billion in 1980—which are sometimes cited as expenditures in the disability field,¹ are not found in the service programs but in income maintenance/health insurance outlays. Beneficiaries of Social Security Disability Insurance (SSDI) are disabled workers under 65, dependent children under age 18, wives with dependent children, a dependent spouse age 62 and over, adults disabled before age 22 who are dependent sons or daughters of entitled or insured disabled workers, disabled widows or widowers, and disabled divorced wives. Eligibility requirements include that the insured person must have sufficient quarters of coverage (have worked long enough to become eligible). At the close of FY 1981, 2,800,000 disabled workers, spouses and children received SSDI benefits. Costs of the SSDI program for FY 1983 are estimated at \$17,594,000,000.

The Social Security Administration also pays benefits to coal miners who have become disabled due to "black lung" disease and their dependents and survivors. The estimate for FY 1983 for this program is \$1,077,000,000.

Another important income maintenance program for disabled persons is the Supplemental Security Income program, popularly known as "SSI."

These benefits go to persons aged 65 and over and to blind and disabled people whose income and resources are below a specified level. The share received by disabled and blind persons in FY 1983 was \$6,500,000,000. SSI recipients are also eligible for Medicare coverage.

The Labor Department provides compensation for disability or death of longshoremen and harbor workers and coal miners disabled by black lung disease and their dependents. The costs of these programs for FY 1983 are estimated at \$4,000,000 and \$446,563,000 respectively.

The Veterans Administration paid pensions to veterans for nonservice-connected disability amounting to \$2,522,552,000 in FY 1983, and compensated veterans with service-connected disabilities with an estimated \$8,030,434,000. The Railroad Retirement Board spent \$665,000,000 on disabled railroad workers during FY 1983.

The total outlay to provide a base income, compensation for disability and pensions to disabled persons amount to \$36,839,549,000. Welfare programs which are administered by the states with financial assistance from the Federal government are another source of income for eligible disabled persons. The health needs of disabled people under a certain income level are met by both Medicare and Medicaid payments. Estimates of how much of these two programs goes to the handicapped population vary widely. The Health Care Financing Administration suggests that 50 percent of Medicaid and 12 percent of Medicare can be allocated appropriately to the disabled population.¹

The importance of Medicaid funds in the disability field cannot be overestimated. An unpublished report prepared in 1981 by the Department of Health and Human Services, Office of Service Delivery Assessment, Region II, states that public spending for mentally retarded persons was estimated at \$11.7 billion of which the Federal portion was \$5.4 billion. Half of public funds was spent on residential care, \$0.7 billion on community residences and \$1.1 billion on care in other long-term care facilities such as nursing homes and mental health institutions. Medicaid dollars became available in 1972 when Congress extended Medicaid coverage to include Intermediate Care Facilities for the Mentally Retarded.

Income Maintenance, Fiscal Year 1983

Social Security Benefits for disabled coal miners	\$ 1,077,000,000
Social Security Disability Insurance (SSDI)	17,584,000,000
Social Security Supplemental Security Income (SSI) for disabled including blind persons	6,500,000,000 *
Labor Department, Longshoremen's and Harbor Workers Compensation	4,000,000
Labor Department, Coal Miners Compensation	446,563,000
Veterans Administration, Pension for Non-service-connected Disability for veterans	2,522,552,000
Veterans Administration, Veterans Compensation for Service-connected Disability	8,030,434,000
Railroad Retirement Board, compensation for disabled railroad workers	665,000,000 *
	<hr/> \$36,839,549,000

*Information received from program office.

Conclusion

To sum up and characterize Federal help for disabled persons, the Federal government makes it its business to:

- help educate handicapped children;
- provide health services through targeted programs such as crippled children's services, developmental disabilities programs, or by paying for the costs for the indigent and medically needy disabled population;
- offer rehabilitation services for disabled workers;
- enable nonprofit sponsors to build housing for disabled persons through loan arrangements;
- make books available to the blind and physically handicapped;
- funnel Title XX money to the states to pay for a variety of social services;
- encourage Mass Transit Transportation Systems to spend funds on services to handicapped citizens;
- fund basic and applied research to prevent, cure, or ameliorate disabling conditions and on technologies to compensate for impairments;
- provide an income floor for disabled persons who have never worked through SSI and welfare payments;
- support disabled workers and veterans through SSDI payments and pensions;
- pay for institutional and residential care through Medicaid and Medicare funds;
- fund special institutions of national significance such as Gallaudet College, the National Technical Institute for the Deaf, the Helen Keller Center for the Deaf-Blind and the American Printing House for the Blind.

More than a score of Federal agencies are involved with the handicapped, but the largest clusters of programs and the largest amounts of money disbursed are in the Departments of Health and Human Services, Education, and the Veterans Administration. As a rule of thumb, funds for services go mostly to the states in the form of formula grants, block grants and categorical program monies. Federal agencies administer funds for manpower development and training, and research and demonstration programs. Income support and insurance monies go directly from the Federal agency to individuals. A certain amount of money is spent on contracts rather than on grants, and contracts are announced in the *Commerce Business Daily*. Grant application announcements are published in the *Federal Register*.

The flow of Federal money in the disability field is not too difficult to track. But at the state level the Federal rivers branch out into many streams and rivulets and Federal money co-mingles with state provided funds. Only a study of individual state budgets and funding could provide us with insights of how much the nation spends in the disability field.

Most of the figures quoted in the above article were taken from the *Catalog of Federal Domestic Assistance* for 1983 (including updates) published by the Office of Management and Budget and available by subscription from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. The cost for the Catalog and the updates is \$32 per year. Sources for the 1984 figures were the appropriation laws or information directly from program offices.

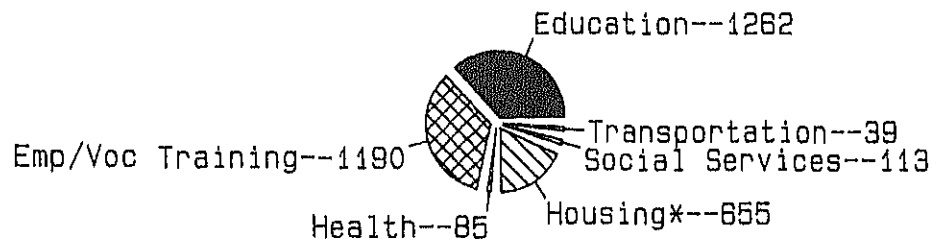
¹*Disability and Work: the Economics of American Policy*. Richard Burkhauser and Robert H. Haveman, The Johns Hopkins University Press, Baltimore, MD 21218, 1982.

FEDERAL DOLLAR SUPPORT FOR THE HANDICAPPED

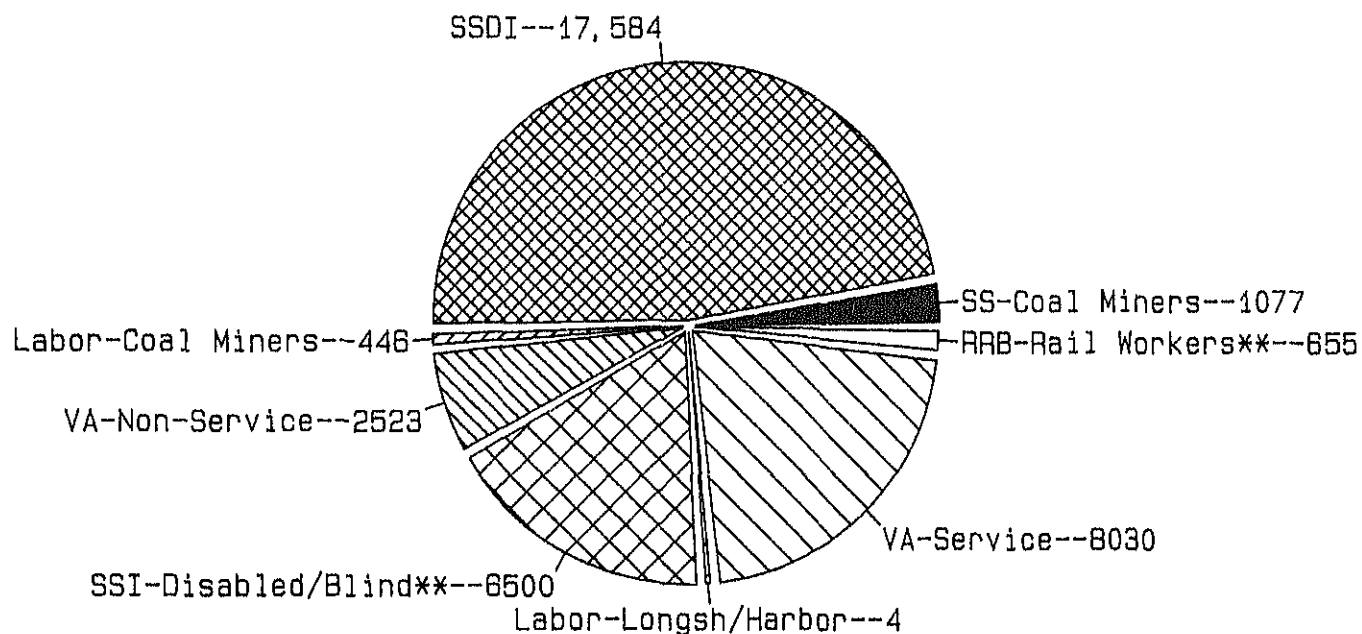
Service and Income Maintenance Programs

Fiscal Year 1983

In Millions of Dollars



SERVICE PROGRAMS



INCOME MAINTENANCE PROGRAMS

**Includes Elderly Non-Disabled.*

***Information obtained from program office.*

High-tech and Low-tech in Rehabilitation

(Excerpts from remarks made by Dr. Douglas Fenderson, Director of the Institute of Handicapped Research at Tufts University, Boston, Massachusetts.)

On February 24th, the National Institute of Handicapped Research (NIHR), in collaboration with the Private Sector Initiatives Office of the White House, hosted a consultative meeting between representatives of several of the largest computer manufacturers and government leaders in the disability and rehabilitation-related fields. The purpose of the meeting was to seek the assistance of computer manufacturers in solving—in the design stage—serious problems of computer access for disabled persons.¹ As you know, this technology is having a pervasive and profound impact on learning, vocations, personal development and leisure. It goes without saying that this information revolution is both a threat and a promise for disabled persons.

Alice Loomer, Ph.D., author of "Hanging onto the Coattails of Science," says, "Modern technology is capable of making the blind almost as if they could see, the deaf as if they could hear, and us (she uses a wheelchair) as if we could walk . . . but the gap between what is possible and what is likely will continue . . ." Specifically, persons with severe sensorial and physical limitations may need special transportable interface devices (Vanderhelden at the Trace Rehabilitation Engineering Center at the University of Wisconsin calls them "emulators"). Computers may not have redundant and auxiliary input ports to allow these special devices to be plugged in without costly adaptation. Similarly, alternative output modes for these groups may be required, and if not anticipated at the time of design may make the devices inaccessible for disabled persons. The cost of these "reasonable accommodations" at the time of design and manufacture is small, but, like the curb-cut, expensive to put in after the sidewalk is laid.

The presentations to industry also affirmed the potential for nondisabled use (and market advantage) for such features of redundancy. Again, using the curb-cut example, Vanderhelden notes that perhaps a hundred bicycles, strollers, and pushcarts use curb-cuts for every wheelchair.

Another problem identified at the White House meeting is with computer operating systems and software. Participants in the meeting concluded that: (a) clearer definition of interface devices was required; (b) that operating systems and software access problems were greater than hardware problems; and (c) representatives of the computer firms would work with NIHR, the National Aeronautics and Space Administration, the Veterans Administration, and other public and private sector groups to attempt "optimizing" solutions to these problems.

The role of technology in this optimizing process is exciting. Last week, for example, I met with an electrical engineer and research physiologist from Belgrade, Yugoslavia. Their group (and a sister laboratory in Ljubljana supported by NIHR) are the pioneers in the use of functional electrical stimulation. This work was given prominent public coverage by Petrofski at Wright State University (the principal investigator was Dr. Dejan Popovic and Dr. Rajko Tomovic was co-investigator). Three NIHR-funded rehabilitation engineering laboratories since 1972 have been conducting controlled studies on the potential for clinical application of these methods and one of the Centers has now produced an important commercial product, the scolitron, which is gaining critical acceptance as an alternative to bracing or surgery for some cases of adolescent scoliosis.

Popovic and Tomovic are making exciting refinements in control technology. By looking at the specific reflex arcs associated with foot, knee and hip, they show that extremely small micro controls at each site, articulated with the others, can achieve function in disabled limbs and obviate the need for large, clumsy computerized apparatus which now attempts complex sequential stimulation and control of muscles for the entire process of ambulation and other functions.

A recent report by the Office of Technology Assessment of the Congress of the United States, entitled "Technology and Handicapped People"² raises the serious issues of cost of technology, commercial viability of many apparently good ideas, fiscal disincentives for commercialization and the lack of adequate distribution, information, and third party payment for adaptive devices. The authors note, for example, that a surgically implanted hip prosthesis is readily accepted as medically important, but a wheelchair or other adaptive device which restores or sustains function may be seen as peripheral and of less importance, and therefore, nonreimbursable.

I want to take this opportunity as well to highlight some additional barriers to "optimizing" human function through rehabilitation technology, and suggest possible future directions. In a provocative article, "Rehabilitation Engineering: The User's Perspective," Joe Bryant reports his survey of users of rehabilitation technology.³ His report is not favorable. He says most disabled persons have never met a rehabilitation engineer. Their impression is that they and their solutions are out of touch with disabled persons, too expensive, not tailored to user needs, and not tested adequately. In a word, they say—the engineers are not listening to the real experts, disabled persons themselves. Bryant notes that the greater the need for adapted technology, the greater the dissatisfaction. He also notes that many disabled persons receive help in designing and constructing such de-

vices from friends and relatives—tinkerers in basements and garage shops—who are accessible, responsive to specific needs, and cheap. Some would like to see a "plan-service," perhaps similar in concept to the service of *Popular Science* magazine which sells plans for do-it-yourself projects for boats, garages, etc. An Australian bioengineer, Mr. E.R. Scull, visited each of our then seventeen rehabilitation technology centers in the fall of 1982. From his perspective, we have it upside down.

Scull was searching for ideas to help him develop a bottom-up approach to rehabilitation technology, based on a public distribution system for adaptive devices. Technicians are more prominent than engineers for modifying devices to individual requirements. Engineers were seen in his country as consultants—a kind of "court of last resort" to solve only the most complex problems.

Although Scull was enthusiastic about the concept of our centers—requiring as they do a collaborative approach between engineers, physicians and other rehabilitation professionals, he finds, in practice, that the team is often a fiction. Doctors do doctoring and engineers do engineering; it is difficult to achieve a sustained interaction. He was also critical of the distance between rehabilitation engineers and the objects of their labors—disabled individuals. Scull says that at least for Australia, the clinical base of technology application is primary. Engineering is an important derivative. We also believe this to be true and are looking for ways to improve or enhance our programs in this respect.

The Scull report and the OTA report are sufficiently consonant as to suggest a shift in emphasis in technology for the disabled. In one NIHR-sponsored study of the use of engineering consultation in vocational rehabilitation, some two-thirds of a group of "non-feasible" clients

achieved vocational outcomes through such consultation. But to capitalize on this potential in the service of our disabled citizens, several questions are posed:

- Can counselors, physicians and other rehabilitation workers be trained to use rehabilitation engineering consultation, much as we use medical consultation in rehabilitation now?
- How can effective collaboration of engineers, physicians and support personnel be assured and sustained?
- How can we "tune in" to the world of reality of the disabled persons we seek to assist?
- What can we do to empower handicapped persons to more efficiently solve their low-technology problems—shall we give them the plans?
- How can government resolve the disincentives problem to commercializing rehabilitation technology?

The rehabilitation process incorporates and transcends technology. It is, in non-euclidian terms, greater than the sum of parts. In rehabilitation we have to follow the great leaders in this field who perceive dimensions of human potential that have fired the imagination of rehabilitation workers and disabled individuals as they seek optimizing alternatives for their lives.

¹A new book by Frank Bowe entitled *Personal Computers and Special Needs* will be available in mid-summer from the publisher, Sybex, 2334 Sixth Street, Berkeley, CA 94710, (415) 848-8233.

²*Technology and Handicapped People*, by the Office of Technology Assessment, Congress of the United States, is available at \$7.50 from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. Stock No. 052-003-00874-2.

³"Rehabilitation Engineering: The User's Perspective," an article by Joe Bryant, was published in *Engineering in Medicine and Biology*, December 1982.

Restructuring Medicaid: An Agenda for Change

A National Study Group on State Medicaid Strategies was formed in the fall of 1982 to analyze the problems of Medicaid, a system under rising pressure to reduce costs at a time when health care service needs are increasing. The Center for the Study of Social Policy, a nonprofit policy research organization in Washington, D.C., received support for the Study Group through a grant from the Robert Wood Johnson Foundation.

The Study Group was composed of nine state Medicaid, Public Health, and Human Service administrators, and it went beyond a diagnosis of the ills of the system and developed strategies that would not only control Medicaid costs but increase the access to the quality of health services to poor people including many disabled and mentally retarded individuals.

Since its enactment in 1965 the federal-state Medicaid program has grown at an astonishing pace. In 1969 the program assisted 12.1 million people at a cost of \$4.4 billion in federal and state payments. By 1982, there were 22 million recipients and the cost had soared to \$29.9 billion.

At present Medicaid is not a single unified program, nor even 54 uniform state and territorial programs, but a collection of programs in each state incorporating multiple objectives, target populations and services. The three major populations now served by Medicaid include:

- Poor families and children who qualify on the basis of Aid for Families with Dependent Children (AFDC) criteria;
- Elderly or other functionally impaired individuals in need of long term care, primarily residents of skilled and intermediate care nursing facilities;
- Mentally retarded and other developmentally disabled persons, most of whom reside in Intermediate Care Facilities for the Mentally Retarded (ICF-MR), institutions and community facilities.

Sixty-six percent of Medicaid recipients—some 15 million people—are eligible through AFDC criteria. The aged and disabled including mentally retarded persons—some 6.3 million people—are eligible as Supplemental Security Income (SSI) recipients. Although this group constitutes only 27% of the Medicaid caseload, it accounts for 72% of expenditures. In 1982 institutional costs for ICF and ICF-MR and Skilled Nursing Facilities accounted for 46% of the total Medicaid payments.

The Study Group found that the objective of meeting the health care needs of poor families has suffered because new federal and state Medicaid dollars have been used largely to meet the rapidly escalating costs of institutional care and that the Medicaid financing system has encouraged expansion of expensive institutional care at the expense of other services such as in-home supports, per-

sonal care and coordination with other human resource programs.

The first and foremost recommendation of the Study Group is to separate primary acute health care from the long-term care for the disabled including mentally retarded and aged and restructure Medicaid into two separate systems of care:

- a federally financed and administered **National Primary Health Care Program** for all low income individuals;
- a state administered **Continuing Care System** which would provide a full range of health and social long term care services to dependent individuals with demonstrated functional impairments.

The federally financed and administered National Primary Health Care Program would, among other features, establish a national eligibility standard replacing widely differing state determined eligibility criteria, establish a health care benefit package emphasizing preventive and primary care especially for families and children, develop a prepaid capitated financing and delivery system and local models of service delivery which perform health education and promotion functions, provide information and referral services and link primary care physicians with necessary health related and non-health related services.

The Continuing Care System would combine health care, social service and personal care needs of the functionally impaired elderly, disabled and mentally retarded.

Some of the key elements would be:

- Federal-state financing with federal dollars provided to states through an indexed capitation grant to a designated state agency.
- States would assume full responsibility for providing all needed care to the two major service populations: 1) the functionally impaired elderly and disabled; 2) the mentally retarded and developmentally disabled.
- Services included in the Continuing Care Program would be: needs assessment, case management, information and referral, in-home and community services and long-term care in a nursing home or other residential facility.
- Continuing care services would be delivered through local agencies.

These recommendations were formulated to remedy some of the shortcomings of the present Medicaid system which does not meet the needs of personal care and social services of the elderly, disabled and mentally retarded and whose financing pattern has made it exceedingly difficult to develop flexible patterns of in-home and community services.

the case management as envisioned in the Continuing Care Program would be an important factor in reducing institutional care and in helping to control costs.

More detailed suggestions on administration and service delivery were developed including financing of continued care and encouraging home care for persons with functional limitations by expanding tax credits to families who provide them. Expected costs of the two systems which could replace the current Medicaid system were carefully studied and the conclusion drawn that there would be no major new outlays.

The National Study Group is now developing cost estimates and working with Congressional staff, and hopes that in the future a legislative proposal can be developed which would incorporate the strategies proposed in the study.

Restructuring Medicaid: An Agenda for Change, the report of the Study Group, is available at \$5 from: Center for the Study of Social Policy, 236 Massachusetts Avenue, N.E., Washington, DC 20002, (202) 546-5062.

New Role for National Council On the Handicapped

The National Council on the Handicapped has received new responsibilities under the Rehabilitation Amendments of 1984 (P.L. 98-221). The Amendments transformed the Council from an advisory body within the Department of Education to an independent agency. The intention is for the Council to function as a "think tank" on issues that affect handicapped persons, to explore the major national issues of concern to disabled people, and to provide advice and recommendations to the Congress, the President, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services, and the Director of the National Institute of Handicapped Research (NIHR).

According to P.L. 98-221, the duties of the Council are:

- 1) establish policies for and review the operation of NIHR—Section 401(a)(1).
- 2) continually review and evaluate all policies, programs and activities concerning handicapped persons which are conducted or assisted by federal funds (such as the Education of the Handicapped Act, the Rehabilitation Act, and the Developmental Disabilities Act) and assess the effectiveness of the policies, programs, and activities—Section 401(a)(4).
- 3) recommend ways to improve research and the administration of services for handicapped individuals, to improve the methods of collecting and disseminating research findings, and to facilitate the implementation of programs based on such findings—Section 401(a)(5).

- 4) submit an annual report on March 31 to the Congress and the President—Section 401(a)(6).

- 5) provide advice, recommendations and additional information to Congress—Section 401(a)(7).

- 6) review all statutes pertaining to federal programs which assist handicapped persons—Section 401(b)(1).

- 7) make a list of federal programs indicating the number of handicapped persons assisted by such programs and the cost of those programs—Section 401(b)(2).

- 8) assess the extent to which such programs provide incentives or disincentives to the establishment of community based services, promote full integration of handicapped persons and contribute to the independence and dignity of such individuals—Section 401(b)(3).

- 9) recommend to the President and Congress legislative proposals for increasing incentives and eliminating disincentives in federal programs based on the assessment above—Section 401(b)(4).

- 10) approve standards developed by the Rehabilitation Services Administration for Projects with Industry (within 90 days after receiving them) by a majority vote at a regularly scheduled meeting (standards must be published by February 1, 1985)—Section 621(d)(4).

- 11) approve standards developed by RSA for Centers for Independent Living (within 90 days after receiving them) by a majority vote at a regularly scheduled meeting (standards must be published by February 1, 1985)—Section 711(e)(4).

The duties listed under 5-11 above are new duties assigned to the Council under P.L. 98-221.

Parent Leaders Transition Conference

Parents have long been recognized as one of the most valuable resources for the education of their handicapped children. Now, when a record number of disabled students are graduating from high school, parents need to focus on the next big steps: independence and integration into the world of work.

To give a helping hand, parent leaders from across the nation were invited to a conference cohosted by three units of the Office of Special Education and Rehabilitative Services (OSERS): External Affairs, the Rehabilitation Services Administration, and Special Education Programs; and by the Federation of Children with Special Needs. The conference was aimed at informing parents on the current issues and potential of the vocational rehabilitation system, how it differs from special education, differences and similarities of how states administer vocational rehabilitation services, and what other types of assistance are in place to help young people in the transition from school to work.

Parents were given the charge to react to the presentations and to identify needed changes in order to make the service delivery system more responsive to the employment needs of disabled youth.

Parents strongly recommend legislation requiring special education, vocational education and vocational rehabilitation agencies to enter into interagency agreements in order to facilitate coordination and cooperation. They would like to see vocational rehabilitation counselors participate in goal-setting for prevocational skills in the Individual Education Plan now in use in school systems for disabled students. They articulated their concern for mentally ill young people who are the most underserved and for the institutionalized who also need more and better services.

Hopes were voiced that the Job Training Partnership Program will be more accessible and more useful for young handicapped people than its predecessor, the CETA program.

A follow-up system for all clients of services was recommended and so was an adult-find system to identify persons who appear to fall between the cracks and receive no services at all. Some recommendations focused on changes in the present vocational rehabilitation set-up such as improved training for personnel, better pay to attract talented people, job training tied to changing labor market demands, and adoption of the concept that training is a lifelong process for everyone and re-entering the system would be facilitated. Sheltered workshops should only be used for transition to other types of employment and not as a final destination.

Finally the parents urged that newly supported work program models—a priority of OSERS—be worked out and that a continuum of parent training programs be funded

and provided. The conference made it very apparent that the challenges for the parent networks around the country are many and demanding, but that there could not be a more willing and eager group of people to take them on.

These parent leaders went home to their states and localities with a host of new ideas, new knowledge about strengths and weaknesses of the existing delivery system, and how to work for improvement in their own communities.

A report on the meeting is available from: External Affairs, OSERS, Room 3132 Switzer Building, Washington, DC 20202.

OSERS to Fight Illiteracy Among Disabled

Illiteracy in our highly complex society is a true "handicap" hampering a person's quest for work, embarrassing him socially and shutting him off from many pleasures. Compound this handicap with a mental or physical impairment and the situation becomes really tragic.

While the nation is gearing up to assault the illiteracy problem, a special effort is underway in the Department of Education to focus on the plight of illiterate disabled persons and to mobilize help. In February 1984 a meeting was convened with representatives of organizations by and for handicapped people, of volunteer groups involved in literacy projects, and professional educational associations to plan for a Disability Networking Conference to be held June 13-15 in Washington, D.C. This conference will set the stage and bring into motion a collaborative effort among organizations traditionally devoted to the welfare of disabled people, of groups which offer volunteer assistance to overcome illiteracy, and of special education professionals who can share experiences on how to best work with people of various disabilities.

The conference has an ambitious agenda and much knowledge of what is and is not available in adult literacy teaching will be brought together. It will address what is needed in terms of funding, accessibility of services to disabled people, and research and development. Model programs will be presented and new education technology such as computers and their applicability to teaching adults to read and write will be discussed. The final charge to the conference is to develop a plan for implementation of the conference recommendations.

Conference participants will hear from the Business Council for Effective Literacy, Inc., a new organization set up with a \$1 million grant from Harold McGraw, Jr., Chairman of McGraw-Hill, Inc., the giant publishing firm. The Council will mainly work through the corporate community and will make research results, professional and technical assistance available to private sector resources.

Another noteworthy contribution comes from B Dalton Bookseller with more than 700 stores nationwide. The \$3 million grant program will fund community programs. The goal is to recruit 50,000 adult volunteers, train and place them.

The Disability Networking Project will give the disability field a chance to get acquainted with these activities and to see to it that many disabled people are among the beneficiaries.

National Media Watch Announced

In January, members of TASH: The Association for Persons with Severe Handicaps, met with a group of media experts to begin a National Media Watch. The initiation of the venture came in response to the TASH Executive Board's decision to address the issue of what messages the world is receiving about persons with handicaps.

Two major thrusts of the Media Watch were proposed by Addie Comegys of TASH: first, the need to translate professional, technical material into lay language for popular journals; and second, the need to set up a network for quick response to the media on any negative images or other misrepresentations that are projected about persons with severe handicaps. An important aspect of this would involve keeping track of situations involving abuses in institutions and reacting to them to effect change.

Among the first activities of the Media Watch included:

- Communicating with Penguin Books of New York to recommend that the book *Annie's Coming Out* (Penguin, Australia, 1981) be distributed in the United States. This book tells the extraordinary story of Anne McDonald who left an institution after 16 years to live with her teacher.
- Beginning a collection of names of those involved in the media who have contributed or are willing to contribute to the effort of presenting to the public, in understandable lay language, pertinent information about severe handicaps and about individuals who have severe disabilities and live in the community. Send names of journalists to TASH.
- Encouraging TASH members to send any articles, information gathered from TV or other reports of instances of abuse in residential facilities to Bob Perske (an especially strong advocate for mentally retarded persons) at 159 Hollow Tree Road, Darien, CT 06820, (203) 655-4135.
- Planning that a panel of media experts will speak at the 1984 TASH Conference (to be held in Chicago, November 8-10, 1984) on ways to influence the media to provide accurate information about individuals who have severe handicaps.

TASH members and friends are encouraged to contribute ideas for future Media Watch activities to: TASH, 7010 Roosevelt Way N.E., Seattle, WA 98115, (206) 623-8446.

MR Offenders Receive Attention

An Individual Justice Plan (IJP) based on the conceptual model of other individualized plans has been introduced in Nebraska as part of a "Special Offender Project."

Crime and Community, Inc. (CCI) of Lincoln, Nebraska and the State Department of Corrections were jointly funded by the Nebraska State Office on Developmental Disabilities (ODD) and the Edna McConnell Clark Foundation to "develop a comprehensive, community-based response to illegal, offending behavior exhibited by developmentally disabled persons who have no historical pattern of violent offenses." The model is designed to facilitate interagency cooperation among the criminal justice, advocacy and DD service systems, thereby building the capacity of communities to deal with disabled offenders from pre-arrest through post parole.

A team of professionals and others involved with the individual are brought together to develop an IJP to enable the person to remain in the community with appropriate support and supervision. Typically a team might include an advocate, a representative of the Department of Vocational Rehabilitation, a teacher, a group home counselor, a case manager and the offender.

CCI also conducts programs aimed at prevention of crimes by DD individuals. One strategy used is to teach police officers how to identify and interact with disabled persons through visits to group homes. At-risk individuals are identified and preventive IJPs are then developed.

For further information and a copy of the *Special Offender Project Training Manual*, at \$5.25 postpaid, write: Jean Morton, Project Coordinator, 129 N. 10th Street, Lincoln, NE 68502.

The New York State Department of Correctional Services has received a grant from the National Institute of Corrections to study the needs of mentally retarded and mentally ill inmates. The project is developing a comprehensive guide for managers of programs for mentally retarded/mentally ill inmates, with emphasis on five areas: an analysis of recent court decisions affecting such inmates and the facilities which serve them; a review of related professional standards; a national survey to determine the number of mentally retarded/mentally ill inmates and their special program needs; the development of model state legislation and sentencing policy; and the formulation of overall state correctional policies and procedures related to mentally retarded/mentally ill persons.

For more information, contact: Frank Tracy, Director, Program Planning, Research and Evaluation, Department of Correctional Services, State Campus, Bldg. #2, Albany, NY 12226.

Vocational Education and Training Policy For Today and Tomorrow

By Richard P. Melia, Ph.D.

"If you have a population that you want to employ, then you redesign the job to get that group working." This profound statement was made by Sue Lerner of the Edison Electric Institute at the National Conference on Vocational Education and Training Policy for Today and Tomorrow, held in Washington, D.C. March 15-16. The emerging theme of the conference was that problems must be approached in a way that is solution oriented.

The conference was sponsored by the National Advisory Council on Vocational Education, the National Center for Research in Vocational Education, the National Commission for Employment Policy, and the Office of Vocational and Adult Education, U.S. Department of Education.

A number of conference presentations and audience reactions had relevance to career preparation, career initiation, and career enhancement for handicapped people. Ms. Lerner noted the importance of examining the impact of the changing demographics of our population (aging population, smaller households and increase in upper income populations) on vocational choices and opportunities. She challenged participants to ask: "How do you define work?" This is an important question for as more and more individuals with severe functional impairments are "aging out" of educational programs, the challenge is to provide transition to jobs structured with necessary supports at the workplace.

The solution oriented approach to problem solving was evident in other ways at the conference. Dr. Robert Taylor, Executive Director, National Center for Research in Vocational Education, spoke on "differential aspects of trends." He noted that "flexibility" and "responsiveness" are code words which will need to characterize our rethinking of "work." He cited the need to examine life-long learning methods and self-directed learning techniques—for all citizens, not just for a technological elite. It should be noted that research activity at Dr. Taylor's Center is making a significant contribution. A recent study published by the Center, for example, has major implications of how handicapped youth are counseled and advised on career choices.

For handicapped people, although Krumboltz did not address this aspect in his monograph, the problem could possibly be compounded by privately held beliefs by some individuals, e.g., teachers, advisors, employers or possible mentors, that an impairment might keep the person from performing a job. In this connection, the American Association for the Advancement of Science's "access to science" efforts have demonstrated positive strategies to let students and employers see, under conditions of flexibility and enrichment in real life situations, how people can be performers.

William P. MacKinnon, Vice President, General Motors Corporation, also stressed flexibility and responsiveness in discussing how GM organizational shifts and changes in product lines have changed the work place and the work force. Similar career planning for handicapped people at the various stages in the vocational development is also crucial.

While the conference did not focus specifically on handicapped workers, information exchanged can be incorporated into training policies and career planning for workers with disabilities as well.

For further information, contact: National Advisory Council on Vocational Education, 425 13th Street, N.W., Suite 412, Washington, DC 20004, or: Dr. Morgan Lewis, The National Center for Research in Vocational Education, Ohio State University, 1960 Kenny Road, Columbus, OH 43210.

The study, *Private Rules in Career Decision Making* by John D. Krumboltz, is an analysis of how generalizations, thoughts, cognitions, beliefs, and skills developed from different experiences are key internal processes which become controlling factors for many individuals in their decision making. As a result of negative privately held beliefs individuals may fail to see a problem, fail to try to solve it, rule out a possible solution, choose the wrong alternative for an inappropriate reason, and possibly suffer anxiety over their inability to reach a desired goal.

Improvements in MR/MH Institutions

The Department of Justice has obtained its first consent decree under the Civil Rights of Institutionalized Persons Act (CRIPA) of 1980. CRIPA, although creating no new substantive rights, gives the Attorney General authority for the first time to take legal action to remedy unconstitutional conditions in state and local prisons, mental hospitals, institutions for mentally retarded persons, juvenile facilities, and nursing homes.

While the consent decree, entered January 18, 1984, in U.S. District Court in Grand Rapids, Michigan, involves conditions of confinement in Michigan's three state prisons, a number of the 42 investigations opened under the 1980 law involve facilities for mentally retarded or mentally ill individuals.

Findings generally show severely overcrowded conditions, fire and safety hazards, poor environmental and sanitary conditions, and inadequate provisions for medical and mental health care. More specifically, officials also found that mentally ill and mentally retarded residents are sometimes over-medicated, improperly restrained and secluded, inadequately supervised, and subjected to physical abuse and neglect.

Institutions that are found to be systematically depriving individuals of constitutional or Federal statutory rights must be notified of the deficiencies and the minimum steps required to remedy them. Under CRIPA, every effort must then be made to encourage state or local officials to correct the deficiencies voluntarily through a process of mediation, negotiation and conciliation, with technical assistance from DOJ attorneys and expert consultants if needed.

Deficiencies have been corrected in many instances without resort to the Attorney General's authority to initiate court proceedings under CRIPA. For example, Illinois State officials have closed the Dixon Developmental Center for mentally retarded persons, and all patients from the Manteno Mental Health Center for mentally ill individuals will be transferred to constitutionally adequate facilities before its closing in 1986. Louisiana State officials have removed patients from several buildings at the Louisiana State Hospital for mentally ill persons and have agreed to improve care and conditions at the remaining buildings. Florida State officials have adopted a master plan to remedy constitutional deficiencies at South Florida State Hospital, a mental health facility.

In other instances, state officials have agreed to renovate or construct new buildings to improve the physical plant of the institutions investigated. Other officials, such as those in Maryland responsible for Rosewood, a facility for mentally retarded persons, have committed themselves to reducing their patient population by placing residents, where appropriate, in alternative community based programs.

Where necessary, the Department has used its authority under CRIPA to intervene in private court proceedings such as *Davis v Henderson*, challenging the constitutionality of conditions of confinement at a Jackson, Louisiana facility that housed more than three hundred persons found either incompetent to stand trial or not guilty by reason of insanity. After attempted cooperative conciliation, a consent decree was obtained requiring compliance with state and Federal standards governing hospitals and health care facilities. The court noted that adherence to these standards, policies, and statutes would help to ensure that the patients receive humane, high quality mental health treatment and care.

As required under CRIPA, the Department of Justice will continue its attempts to avoid prolonged litigation, to promote a spirit of cooperative conciliation, and to resolve constitutional violations as expeditiously as possible.

Residential Facilities For MR Surveyed

The Center for Residential and Community Services of the University of Minnesota has reported the preliminary findings of its 1982 census of residential facilities for the mentally retarded. The research was supported by a grant from the Health Care Financing Administration, Department of Health and Human Services.

For the purpose of the survey, the term "facility" included any living quarters providing 24 hour, 7 days a week responsibility for room, board and supervision of mentally retarded people with the exception of family homes providing services to a relative, nursing homes, boarding homes and foster homes that are not state licensed or contracted as mental retardation service providers, and independent living (apartment) programs which have no staff residing in the same facility.

According to the census, as of June 1982, 243,669 mentally retarded individuals lived in 15,633 facilities and specialized foster homes. Sixty-two percent of the facilities were operated by proprietary organizations and provided services to 24% of the residents; 31%, accommodating 23% of the residents, were operated by non-profit organizations; 83.6% indicated that they were members of a system, that is, in a group of facilities operated by the same individual or organization.

The total number of mentally retarded residents in privately operated facilities ranged from one to 710. Half of these facilities had four or fewer residents. Only 5% of privately operated facilities served more than 20 residents. In publicly operated facilities the number of residents served ranged from one to 1896. Approximately 83% of mentally retarded persons residing in publicly operated facilities lived in residences accommodating more than 250 individuals. Three percent of these facilities served 10 or fewer residents.

Other findings include 55.5% of all residents were males, 44.5% females; approximately 25% were under 22 years of age, 40% of the total population was characterized as borderline, mildly or moderately retarded while 60% were reported as severely or profoundly retarded. A higher percentage of residents in public facilities were classified as severely or profoundly retarded

More comprehensive reports on the 1982 census including analysis of trends in residential services since 1977 when the first census was undertaken will be published by the Center for Residential and Community Services, University of Minnesota, 207 Pattee Hall, 150 Pillsbury Drive, S.E., Minneapolis, MN 55455.

Revised Criminal Justice Mental Health Standards

Criminal justice agencies and institutions have to deal daily with people who are mentally ill or mentally retarded. Members of the legal and mental health professions have been grappling with these cases for a long time. But the alliance between psychiatry and the law has been an uneasy one. The law teaches its practitioners to be judgemental; psychiatrists, psychologists and other mental health professionals tend to "explain" behavior rather than "blaming" it. The role and function of mental health in criminal justice has not been clearly defined, and "legal insanity" has been a topic of hot contention among scholars and the public alike.

The American Bar Association (ABA), recognizing that the subject of mental health issues in criminal law has not received adequate attention in its *Standards for Criminal Justice*, launched in 1981 its Criminal Justice Mental Health Standards Project with the help of a million dollar grant from the MacArthur Foundation. The project was aware that its subject matter was interdisciplinary in character, and from the beginning involved mental health and legal practitioners and established formal liaisons with a host of non-legal professional organizations such as the American Psychiatric Association, American Psychological Association, American Orthopsychiatric Association, and National Sheriffs' Association, and drew on the support and expertise of the National Mental Health Association and the National Alliance for the Mentally Ill.

The fruit of the labor of the project has become available in the form of a first draft of *Criminal Justice Mental Health Standards*. These standards have not yet been approved by the House of Delegates or Board of Governors and therefore do not constitute the policy of ABA, but the 91 individual but related standards tell where the ABA is heading. They cover the entire gamut of mental health issues:

- Mental Health, Mental Retardation and Criminal Justice: General Professional Obligations
- Police and Custodial Roles

- Pretrial Evaluation and Expert Testimony
- Competence to Stand Trial
- Competence on Other Issues
- Nonresponsibility for Crime
- Civil Commitment of Insanity Acquittes
- Special Dispositional Statutes
- Sentencing Mentally Ill and Mentally Retarded Offenders
- Mentally Ill and Mentally Retarded Prisoners

The chapters address in very specific terms where better inter-profession communication could contribute towards improved understanding and performance. The project dealt with the frequent inadequacies of existing mental examinations and points toward better use of mental health sciences and professions

The ABA welcomes comments on these draft standards. Copies of the *First Tentative Draft. Criminal Justice Mental Health Standards* are available free while supplies last from: Director, Criminal Justice Mental Health Standards Project, American Bar Association, 1800 M Street, N.W., Washington, DC 20036.

Community Based Rehabilitation Services

Community based rehabilitation services is a concept developed and propagated by the World Health Organization (WHO) as part of its drive towards "health for all by the year 2000." It is a very timely concept not only for Third World Countries suffering from lack of rehabilitation facilities, trained personnel and funds, but also for developed industrialized countries where disenchantment with institutions as warehouses for disabled persons is growing and self-help and self-determination groups among the disabled population are striving for community based solutions to problems.

Applicability of community based rehabilitation services to the U.S. was explored during a seminar cosponsored by the World Rehabilitation Fund and the National Institute of Handicapped Research held in Washington, D.C. on March 28-30. The basis for discussion was a monograph developed by Dr. Antonio Periquet, a fellow of the International Exchange of Experts and Information Program of the World Rehabilitation Fund, in which he documented the implementation of the WHO project in Bacolod, a community on one of the islands of his native country, the Philippines.

Community based rehabilitation services as blueprinted by WHO is a three tier primary health care approach for disability prevention and rehabilitation which envisions trained community volunteers as the first care-givers, an intermediate support level where doctors, nurses and other auxiliary personnel are available, and a specialized service level providing medical and vocational rehabilitation by trained personnel for the most difficult cases.

While many developing countries have a modicum of specialized services available at least in their capitals or urban areas, the intermediate and community based rehabilitation services need to be developed.

Dr. Periquet's project started at the community level. Community volunteer workers, called "local supervisors," were recruited and trained with the help of a WHO developed manual and training packages. Technical expertise came from the Department of Rehabilitative Medicine of the University of the Philippines which helped with the revision of the WHO manual and with evaluation of patients. Government and non-government agencies made resources available and accepted referrals from the local supervisors for educational, employment training, and social welfare services among others.

When asked about the community volunteer workers and potential problems in keeping them involved, Dr. Periquet pointed out that they received token gifts but that their most important reward was the increased status they enjoyed in the community since they have taken on this job. The pilot program conducted in Bacolod proved that the provision of simple, low-cost rehabilitation services in rural areas is indeed possible. Lessons for future implementations include that strong community involvement and backing by local governments are absolutely essential and that integration of community based rehabilitation services into existing programs such as community development or primary health care programs would strengthen chances for success.

Participants in the seminar were rehabilitation professionals based in the U.S., and people who operate programs in the Caribbean, Mexico, and the Southern Hemisphere. Successful involvement of parents of handicapped children who were taught to help other parents with their disabled youngsters was reported from Kingston, Jamaica. Handicapped villagers learned to make simple prosthetics through Project Projimo in Mexico (see "New Publications").

Since the U.S. rehabilitation delivery system is largely institution-based the discussion revolved around strategies to interface a community based rehabilitation approach with the present system. One of the main advantages of community based rehabilitation services appears to be the opportunity to involve disabled persons and their families much more in the rehabilitation process, to develop disabled leadership for local services, and to provide training for "upward mobility" to handicapped individuals.

While in the Third World countries community based rehabilitation services are dictated by economic necessity and the harsh realities of existence, they present an opportunity in the industrialized world to return some very basic human values to our society by mobilizing families, neighbors and volunteers to recognize the needs of their fellow disabled citizens and respond to them. The monograph on community based rehabilitation services by Mr. Periquet will be available from The World Rehabilitation Fund, 400 East 43rd Street, New York, NY 10016, (212) 679-2934.

Strategies in Independent Living: A New Report

Challenges of Emerging Leadership: Community Based Independent Living Programs and the Disability Rights Movement is a new report based on a five-day intensive "Independent Living: Leadership Strategies" conference held in August 1982. The conference was supported by a grant from the Charles Stewart Mott Foundation and was attended by 21 leaders in the independent living and disability rights movement.

The report reaffirms the philosophy of independent living by spelling out its basic principles, emphasizes the importance of the role of the independent living movement for the disability rights movement, identifies problems facing the movement, and makes recommendations of what needs to be done to ensure a healthy future for independent living centers (ILCs).

Three basic principles constitute the philosophy of the independent living movement:

- disabled persons design and run their own programs;
- programs are community based and community responsive;
- programs provide services and undertake advocacy for change in the broader community.

A major problem in translating this philosophy into programs, budgets, and organizational structure identified in the report is that these activities must be acceptable to the Federal government which provides 80 percent of the expenditures of independent living centers under Title VII of the Rehabilitation Act Amendments of 1978. According to the report rehabilitation professionals in the state agencies have seen independent living as an alternative form of services for disabled individuals for whom employment is not a feasible objective. Independent living center program directors say that independent living encompasses employment, but only as one of the ways an individual can achieve independence. Tension has also been caused because a wide range of program models have sprung up under the rehabilitation system which are not run and directed by disabled people and do not include community advocacy.

The Independent Living Leadership Strategy conference looked at these conflicts from a grassroots perspective and attempted to propose solutions that will assist the community based movement and enhance the rights of disabled people.

Almost total dependence of the ILCs on Federal funding creates control problems and uncertainty since Federal funding is not usually long-term. Existing centers have to compete with newly created centers for scarce funds. Diversification of funding is necessary but limited by a host of barriers such as the image of disabled people as "deserving poor," dependent and helpless among the fundraising world, the inexperience of program directors in

the art of fund-raising, and boards of directors of ILCs which lack community clout and connections

A second issue identified by the conference participants is leadership development and direction. Disabled leaders must develop their own resource base and power structures to maintain the integrity of their programs and goals. Thirdly, assistance is needed in organizational development and management skills on the parts of the directors and staff of ILCs. Finally, since independent living programs are both service providers and catalysts for community change, ability to educate the community and to build strong relationships of support are seen as critical.

The recommendations made by the conference participants are a challenge to existing ILCs and to the disability movement. They include:

- Creation of an assistance network among ILCs to provide peer support, share successful solutions, generate packages which address common managerial problems such as accounting for non-profits and job descriptions,

and develop representation of ILCs for media, foundations, corporate funding sources, policy-makers and community people

- Develop a capacity within the independent living/civil rights movement to carry out long term planning and policy development and undergird these activities with applied research.

- Assist the disabled community as a whole to meet its goals of social, economic and political participation in the broader community.

The report highlights eloquently the aspiration of disabled people to achieve independence, rely on self-support, advocacy and self-determination, and emphasizes the role of the independent living movement in achieving these goals.

Challenges of Emerging Leadership. Community based Independent Living Programs and the Disability Rights Movement is available at \$5.95 postpaid from: Publications Director, The Institute for Educational Leadership, 1001 Connecticut Avenue, Suite 310, Washington, DC 20036, (202) 822-8405.

Monitoring the Development of At-Risk Infants

(The following excerpts are from a report by Diane Bricker, Ph D, Ann Marie Jusczyk and Linda Mounts on a study of a low-cost system to monitor the development of at-risk infants at the University of Oregon, Center on Human Development. The study was supported by a grant from the National Institute of Handicapped Research.)

Detection and intervention efforts have been broadened in the 1980's to include increasingly younger handicapped children, and infants at risk due to medical or environmental reasons. The motivation for these trends appears to arise, in part, from a belief shared by many researchers, practitioners and parents that early intervention can be beneficial for handicapped infants and infants at risk of developing problems which will interfere with their subsequent growth.

A basic requirement for early intervention is that tests or procedures be made available that can accurately identify those infants who will require intervention and those who will eventually outgrow their problems without intervention. To overlook infants who have problems that either persist or become more serious as they grow older is costly and ultimately wasteful both to the family and to society.

Although severe handicapping conditions in infants are usually recognized within a few weeks after birth, mild to moderate problems can often go undetected by parents during the first years of life. Such conditions may also be overlooked by health professionals who are not always well-trained to recognize developmental problems, especially during the first two years of life. On the other hand, many infants who have medical problems that require

special care soon after birth then develop normally without any further special attention.

Many developmental centers around the country have professional personnel who are specifically trained to examine and diagnose problems in infants. However, these assessments are too costly for routine screening of all at-risk infants. The dilemma, then, is to be able to accurately identify infants who will require some form of intervention in order to overcome their specific problems, accurately identify infants who can be expected to outgrow their problems without intervention, and perform the assessments most economically.

One possible solution to this problem would be to ask parents to assist in monitoring the development of their infants during the first two years of life. A number of research projects have reported success in such an endeavor. However, some of the projects were limited in scope or not necessarily applicable to an at-risk population. Consequently, in 1980 the National Institute of Handicapped Research awarded a grant to the University of Oregon, Center on Human Development, to develop and determine the usefulness and cost of a system that would have parent assistance in monitoring the development of their at-risk infants over a period of time.

A set of six questionnaires was designed to be completed by parents at four-month intervals for the first two years of their infants' lives. Each questionnaire contained questions about the infant's development with a chance to express any special concerns, and were in a postpaid mail-back format. The questionnaires contained sections on
(See *At-Risk Infants*, page 20)

News Briefs

EHA Amendments Include 0-3 Year Olds

Children from birth to three years of age will be added to the age range of children who may receive special education and related services under the Education of the Handicapped Act (EHA) Incentive Grants program, according to a notice of proposed rulemaking published in the March 21, 1984, *Federal Register*.

The authorization for changing the age range of children served under Section 619 of EHA from three to five to birth through five was granted by P.L. 98-199, the Education of the Handicapped Act Amendments of 1983.

Research studies of the past decade confirm that early identification, diagnosis and treatment of handicapping conditions can significantly reduce the number and severity of handicaps in later life. Early efforts to reduce the limiting effects that physical and cognitive impairments have on major life functions increase the potential benefits of the educational system.

States may expand services to children from birth to age three at their discretion; Section 619 does not **require** services to this group. However, states that elect to serve such children will need to amend their approved applications for Fiscal Years 1984-86.

New Mexico Joins P.L. 94-142

Governor Toney Anaya of New Mexico recently signed into law a bill ending the state's historic opposition to accepting federal grants for education of handicapped children. The new law requires the state education department to apply for federal money under the Education for All Handicapped Children Act (P.L. 94-142).

At its March 2 meeting, the state board of education voted 9-1 to order the state education department to start drafting the plan to serve handicapped children which must be submitted to the U.S. Department of Education before the state can receive 94-142 funds. One board member felt the state legislature had overstepped its authority by requiring state participation in 94-142. At the request of the board, the New Mexico attorney general's office issued a preliminary opinion on the constitutionality issue. The assistant attorney general said that "the legislature does have the authority to require the state's participation under 94-142," giving the state special education department the right to draft the plan.

Independent Living Programs Surveyed

The Independent Living Research Utilization project at the Institute for Rehabilitation and Research in Houston, Texas, has recently conducted a major re-survey of independent living programs. A synthesis of survey findings will be included in future issues of ILRU INSIGHTS, the newsletter for those involved in the field of independent living.

Returned survey information was also used to update their *Directory of Independent Living Programs*, a printout containing names, addresses, and telephone numbers of 279 programs providing independent living services across the country. To obtain the Directory, send a check or money order for \$8.50 to: ILRU, P.O. Box 20095, Houston, TX 77225.

Bowe Joins ATBCB

Dr. Frank Bowe, noted author of many books in the disability field, has joined the staff of the Architectural and Transportation Barriers Compliance Board as communication barriers specialist. Dr. Bowe will look into barriers encountered by blind and visually handicapped, deaf and hard of hearing, and deaf-blind individuals in public buildings, public transportation and other public environments. With Dr. Bowe's assistance the ATBCB will identify problems and seek solutions.

One study Dr. Bowe has already prepared is "Alarms and Alarm Systems: Audible, Visual, Specialized and Sensory, and Personal Signalling Systems," a technical paper on the state-of-the-art in alarms and alarm systems as technologies developed in recent years relate to persons with disabilities. Professionals in alarm technologies may order the paper from: A&TBCB, Office of Technical Services, 1010 Switzer Building, Washington, DC 20202, (202) 472-2700.

Law Reporter Takes New Name

The *Mental Disability Law Reporter*, published by the American Bar Association, has changed its name to the *Mental and Physical Disability Law Reporter* because it contains articles on important cases, decisions, laws, codes, regulations and other matters that impact on both mentally and physically disabled persons. The bimonthly publication, now in its eighth year, is available at \$90 for individuals and \$135 for agencies and institutions from: Mental and Physical Disability Law Reporter, ABA, 1800 M Street, N.W., Washington, DC 20036, (202) 331-2200.

Announcements

Social Security Demonstration Project

The Social Security Administration has announced a demonstration project for continuing Supplemental Security Income (SSI) benefits to certain disabled recipients who are working and for continuing Medicaid eligibility to certain disabled and blind recipients whose SSI benefits were discontinued because of earnings. The project, which was announced in the March 15 *Federal Register*, is for the period January 1, 1984 to December 31, 1984.

The purpose of this demonstration project is to obtain more data to decide whether permitting work by severely impaired recipients while continuing their SSI benefits and/or Medicaid eligibility status is an incentive for these recipients to begin or continue with work.

For additional information, contact Mrs. Theresa Nowinski-Lelter, Office of Supplemental Security Income, Social Security Administration, 3-R-2 Operations Building, 6401 Security Boulevard, Baltimore, MD 21235, (301) 594-4387.

"Exploring Your Brain"

The Epilepsy Foundation of America (EFA) has received a \$27,000 grant from Parke-Davis to disseminate its new computer program about the brain to secondary school science departments throughout the U.S. The grant will enable EFA to make the computer program called "Exploring Your Brain" available free to over 12,000 schools.

"Exploring Your Brain" is a four-unit, computer-assisted instruction program which includes information on the geography and circuitry of the brain, function and malfunction, and the social response to brain malfunctions. Information on epilepsy is included in the program, which comes in the form of a floppy disc for use in Apple II computers.

"This program is not only a new use of new technology, it is also an entirely new approach to our basic goal of getting factual information about epilepsy to young people," explained Nyrrna Hernandez, deputy executive vice president for program services. "Most epilepsy education materials are designed to use in health education classes. 'Exploring Your Brain' is a way to focus on the scientific basis of this disorder, and to de-mystify it through this emphasis."

Information about the program and order forms have been sent to 2,000 schools and EFA affiliates, with an extremely favorable response.

For further information contact: Epilepsy Foundation of America, 4351 Garden City Drive, Landover, MD 20785. Telephone: (301) 459-3700.

United States-Israel Agreement Announced

The United States and Israel recently announced a bilateral agreement of cooperation in social services and human development. A Memorandum of Understanding was signed by Health and Human Services Secretary Margaret M. Heckler and endorsed by Aharon Uzan, Israeli Minister of Labour and Social Affairs.

"This special new working relationship . . . is an important step forward for both countries," Secretary Heckler said. "Exchanges of information . . . and experts . . . are bound to help solve . . . social welfare problems for people in both countries as well as people everywhere."

The agreement, which will be in effect for five years, calls for cooperation in adoption of children with special needs; community and in-home services for functionally impaired populations; innovative housing arrangements for the aged; intergenerational linkages; developmental disabilities; work-related and in-home day care; access to services by the handicapped; and the prevention of juvenile delinquency and rehabilitation of juvenile offenders.

Overall coordination for the United States will be the responsibility of HHS's Office of Human Development Services and, for Israel, the Department of International Relations of the Ministry of Labour and Social Affairs.

New Deaf-Blind Communication Aid

Telesensory Systems, Inc. (TSI), a world leader in the design and manufacture of sensory communication aids for visually impaired people, has announced the manufacture of TeleBraille, a revolutionary communication system which could unlock communication with people who are both deaf and blind. A deaf-blind person who knows braille can learn to operate the TeleBraille system in a few minutes. The person "talks" by keying in his message on a braille keyboard and "listens" by reading a braille display consisting of several rows of pins that are mechanically raised and lowered to display 20 cells of braille. A sighted partner "talks" by keying his message on a typewriter keyboard built into a second unit connected by a cable to the braille unit. This second unit also contains a 32 character visual LED display and a telephone acoustic coupler. Information from either keyboard appears simultaneously on the visual and braille displays. The system is battery operated and portable, and can also be used for communication over the telephone. For more information, contact: TSI, 455 North Bernardo Avenue, Mountain View, CA 94043-5274, (415) 960-0920.

NEW PUBLICATIONS

FUNDING DIRECTORY

The *Handicapped Funding Directory*, 1984-85 edition, is now available. A major source of information for planners and fund seekers, the Directory lists more than 600 foundations, corporations, government agencies, and associations which grant funds to institutions and agencies for programs and services for handicapped individuals. The Directory includes essays on grantsmanship, addresses of State Agency directors, and a bibliography of grant funding publications. A paperback copy of the Directory is available at \$18.95 postpaid from: Research Grant Guides, P.O. Box 357, Oceanside, NY 11572.

REHABILITATION

People interested in community based rehabilitation should take a good look at "Project Projimo," a villager-run rehabilitation program for disabled children in Western Mexico. In this project, community rehabilitation workers—many of them disabled young people—provide simple orthopedic and rehabilitation services to disabled village children. They pick up their skills—not through formal education—but by informal training and on-the-job learning from professional therapists and orthotists who come for short-term visits to the project. The coping skills learned by being disabled themselves are enhanced by brief apprenticeships in various orthotic and prosthetic centers where they are trained in the production and repair of simple aids. Family members and other villagers are involved in many of the activities of the project. Handicapped and non-handicapped children play together in a playground made by village children, and popular theater is used to present simple skits about helping, about disabled people and about the rehabilitation work. A description of how the project works, how it is funded, and what it has accomplished has been published in a richly illustrated booklet, *Project Projimo*, available at \$5 from: Hesperian Foundation, Box 1693, Palo Alto, CA 94302.

RESPIRE CARE

Respite Care Co-op Program Manual and *Parent Respite Care Exchange Handbook* are now available as a set. The program policies and procedure manual and the handbook for training parents in receiving and giving respite care, were developed by parents and professionals who organized a parent-operated respite care program. The Family and Children Services of Kalamazoo and the Kalamazoo Association for Retarded Citizens started the program under a grant from the Administration on Developmental Disabilities. The 1983 publications are available for \$7.50 from: Family and Children Services, 1608 Lake Street, Kalamazoo, MI 49001, (616) 344-0202. Information on the respite care model itself is available from: Care Co-op Consultants, 2324 W. Main Street, Kalamazoo, MI 49007, (616) 345-5338.

INDEPENDENT LIVING

Independent Living and Policy Changes. Reflections on a Decade's Progress is a new publication of the Independent Living Research Utilization (ILRU) project in Texas. It identifies six key areas in which leading figures in the independent living movement of the last ten years called for substantial changes. It describes the changes that were recommended, and then assesses the extent to which these changes have been implemented. The six areas are: entitlement to rehabilitation services, transportation, housing, employment opportunities, elimination of architectural barriers, and elimination of communication barriers. *Independent Living and Policy Changes* is the fifth monograph in ILRU's "Issues in Independent Living" technical report series. To order, send your name, address, and a check or money order for \$5 to: ILRU Project, P.O. Box 20095, Houston, TX 77225. Allow up to six weeks for delivery.

LIBRARY SERVICES

That All May Read: Library Service for the Blind and Physically Handicapped is a 518-page volume intended to provide students, professionals and others in the field with a practical guide to programs and resources. The book describes how a number of agencies, including the Library of Congress, have changed and expanded their programs and developed standards over the years. A review of federal legislation evaluates the effectiveness of various laws designed to enhance the lives and educational opportunities of visually and physically impaired individuals. The book includes chapters on reader characteristics, reading aids and devices, state programs, the National Library Service network, school library and media services, public libraries, training and research, and international activities. An extensive bibliography is included. The book is available without charge from: Publication and Media Section, National Library Service for the Blind and Physically Handicapped, Library of Congress, Washington, DC 20542.

AWARENESS

Show Me No Mercy by Robert Perske is the story of a family with teenage twins, one of whom has Down's Syndrome. It centers upon the father and son who overcome almost impossible obstacles to be reunited and whose struggle touches the lives of an entire community. Perske has been a journalist and free-lance author of award-winning nonfiction, and now demonstrates his skill at weaving plot and characters into a fascinating human drama. This 144 page soft cover book is available at \$7.95 from: Abingdon Press, 201 Eighth Avenue South, Nashville, TN 37202, (615) 749-6290.

NEW PUBLICATIONS

EDUCATIONAL MATERIALS

The Sister Kenny Institute in Minnesota has published its Spring 1984 Educational Materials Catalog, a listing of books, films, videocassettes, slide/tapes, audiocassettes, slide/scripts and microcomputer courseware for health professionals. The Institute is a comprehensive rehabilitation hospital, a division of Abbott Northwestern Hospital. It pioneers in innovative treatment techniques, disability prevention, research and education, and the production and distribution of multi-media educational materials which assist disabled persons to reach optimal function and independence. The catalog is available from: Publications and Audiovisuals Office #E, Sister Kenny Institute, Abbott Northwestern Hospital, Inc., 800 East 28th Street at Chicago Avenue, Minneapolis, MN 55407, (612) 874-4175.

A Spring 1984 *Educational Materials* catalog has been published by Applied Systems: Instruction Evaluation Publishing (ASIEP), a listing of computer software and materials for health professionals who are assessing, developing educational plans and evaluating progress for autistic, severely handicapped or developmentally disabled students. The catalog is available from: ASIEP Education Co., Dept. A4, 3216 N.E. 27th Avenue, Portland, OR 97212, (503) 281-4115.

High-Risk Infants

(Continued from page 16)

gross motor, fine motor, communication, social/personal and adaptive development. Staff cooperated with parents by telephone to encourage completion and return of the questionnaires.

The system was designed to determine: 1) how well the parent-completed questionnaires agreed with assessments of the infants by trained examiners using a standardized infant development test; 2) how well the parent completed questionnaires agreed with questionnaires completed by infant development specialists; and 3) the cost of using the questionnaire system.

To answer the first question, assessments performed by trained examiners at four-month intervals using the Gesell Developmental Schedules were compared with the questionnaires returned by the parents. At the close of the test period, it was calculated that on the average 83 percent of the parent evaluations agreed with the assessments of the examiners.

The second question was answered by comparing the parent questionnaires with those completed by trained

HEALTH INFORMATION

A revised and updated directory, *Health Information Sources in the Federal Government*, has been published by the Office of Disease Prevention and Health Promotion, HHS. It has been expanded to encompass 113 selected federal and federally sponsored health information resources that the staff of the National Health Information Clearinghouse have found useful in responding to health inquiries. Each entry contains a description of the medical services and activities, any known limitations, and charges for services. Information about publications and access to data bases is included. While supplies last, single copies are available without charge by sending a self-addressed mailing label to: National Health Information Clearinghouse, Dept. HI, P.O. Box 1133, Washington, DC 20013-1133.

professionals. In this comparison, it was determined that the questionnaires filled out by 70 parents and by professionals were in agreement 90 percent of the time.

Question three was answered by determining the cost using the questionnaire system once it had been developed. The costs for printing, telephone calls, stamps and personnel came to approximately \$15 for each family that received the complete set of six questionnaires.

Data from this study and other investigations make clear the dilemma inherent in screening programs for at-risk infants. For various reasons, no system will always identify those infants who need intervention and those who do not. However, it was encouraging to learn that most parents can accurately monitor the development of their infants, freeing professional resources to monitor others. Current data also suggested that 85 to 90 percent of the at-risk infants were found to be functioning within the normal range by both parents and professionals, thus requiring additional monitoring for only 10 to 15 percent of the infants.

Another important feature of this system was its cost. Approximately \$2.50 per questionnaire a community agency could employ this system which appears able to accurately identify the majority of babies who are developing without problems and those who will require some form of intervention.

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